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DEAFNESS — DISABILITY OR SUBCULTURE: THE EMERGING CONFLICT

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INTRODUCTION

Since the 1988 Gallaudet University[1] "Deaf President Now" movement, which resulted in the appointment of the University's first Deaf[2] president, the issue of "Deaf Culture" has received substantial media attention.[3] The featured cover article in the September, 1993 issue of *The Atlantic*,[4] entitled "Deafness as Culture," serves as an example. The author explores the beliefs of Deaf culture advocates who argue that deaf people are not handicapped and deafness is not a disability. These advocates assert that deaf people constitute a "subculture like any other," a "linguistic minority" who speak American Sign Language, and thus "are no more in need of a cure for their

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[1] Gallaudet University, located in Washington, D.C., is the world's only liberal arts university for deaf people.

[2] People who live in a Deaf cultural environment have chosen to live primarily in a segregated "Deaf" world. They capitalize the word "Deaf" to illustrate the difference between members of that Deaf cultural environment and other deaf people who have chosen to live as part of the mainstream society.

[3] *See, e.g.*, *Gallaudet's Presidential Quest*, CHRISTIAN SCI. MONITOR, Mar. 14, 1988, at 15; Nicholas C. McBride, *Civil Rights Win for the Deaf: Gallaudet Students Hail Symbolism of Deaf President*, CHRISTIAN SCI. MONITOR, Mar. 15, 1988, at 3; *The Deaf are Heard*, N.Y. TIMES, Mar. 18, 1988, at A34; Molly Sinclair, *Protesters Demand a Deaf President*, WASH. POST, Mar. 8, 1988, at A1; Carlos Sanchez & Molly Sinclair, *Students Hail Zinser Resignation: Protest Continues as Gallaudet Seeks to Restore Order*, WASH. POST, Mar. 12, 1988, at A1; Molly Sinclair & Carlos Sanchez, *Gallaudet U. Selects First Deaf President: Board Chief Resigns; Student Demands Met*, WASH. POST, Mar. 14, 1988, at A1; Molly Sinclair, *Gallaudet Greets Its New President*, WASH. POST, Mar. 15, 1988, at A1.

[4] Edward Dolnick, *Deafness as Culture*, ATLANTIC, Sept. 1993.

condition than are Haitians or Hispanics."[5] The television networks have also featured programs discussing the Deaf culture movement,[6] particularly in the context of considering whether deaf children should receive cochlear implants.[7]

However, the legal and moral ramifications of the contention that deaf people are not disabled have yet to be addressed.

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[5] *Id.* at 37. American Sign Language (ASL) is a language completely different from English. It has its own grammar and syntax and is based on the use of signs representing a limited number of concrete terms. ASL qualifiers generally follow rather than precede the noun; events are normally placed in chronological order; cause and effect relationships are generally stated in the form of rhetorical questions; and conditional phrases are usually placed last in a sentence. By way of example, a person signing or writing ASL might state "[y]our true most need tell me must," while a speaking person would state "[y]ou must tell me what you really need most." J.K. KRESSE & P. KLEVEN, DEAF PEOPLE AND SIGN LANGUAGE INTERPRETERS IN COURT: A BOOKLET FOR BENCH AND BAR 7 (1981).

[6] *See, e.g., Sixty Minutes* (CBS television broadcast, July 11, 1993) (report on child with a cochlear implant); *Inside Edition* (syndicated show, Dec. 24, 1993) (report on two young children born deaf who now hear with the help of cochlear implants).

[7] Cochlear implants are electronic prostheses implanted into the inner ear that partially perform the functions of the cochlea — "the hearing portion of the inner ear that transduces sound waves into coded electrochemical signals." Thomas Balkany, *A Brief Perspective on Cochlear Implants*, 328 NEW ENG. J. MED. 281, 281 (1993). The cochlear implant is intended to remedy many of the ramifications of the most common form of deafness: nerve deafness. "Because most nerve deafness is caused by the dysfunction of receptor cells (the hair cells of the organ of Corti), more proximal neural elements remain available, can be stimulated electrically, and can conduct impulses to the auditory cortex." *Id.* The implanted prosthesis is hooked up to an exterior processor, which is "programmed" via computer to create an individual "map" for the particular implantee that sets the high and low thresholds of sound for each of 21 separate wires that have been implanted into the inner ear. Noel L. Cohen et al., *A Prospective, Randomized Study of Cochlear Implants*, 328 NEW ENG. J. MED. 233, 233 (1993).

Currently, the people who receive the most benefit from cochlear implants are: (1) those deaf persons who once had hearing but lost their hearing later in life (these people have auditory memory and training) — those who have been deaf for the shortest periods of time usually receive the most benefit; (2) those deaf persons who, although deaf all or most of their lives, have worn hearing aids for a long period of time and have received much benefit — including some speech discrimination — from the hearing aids (those people also have auditory memory and training); and (3) very young deaf children, who are implanted before they have been deafened for a lengthy period of time. All cochlear implantees, however, whatever their status or prior history, require auditory training to assist them in learning to process the sounds they receive via the implant.

If deafness is a state of being that should not be altered, even if alteration were possible, should deaf people be entitled to benefit from laws requiring society to pay for disability related costs? Deaf culture advocates are on the brink of an important, yet unrecognized, dilemma.

I. THE TRAIN TO TECHNOLOGICAL PROGRESS

During the last twenty years, major technological advances have assisted people with hearing impairments. Hearing aids have improved tremendously with respect to both quality and aesthetics. By blocking out background noise and emphasizing sound in the speech range, the newer hearing aids have enabled some severely and profoundly hearing-impaired people[8] to benefit from hearing aids for the first time.[9] Assistive listening devices — such as improved FM systems[10] — have opened up new avenues for people with moderate to severe hearing loss. Cochlear implants have enabled some profoundly deaf people to understand speech without having to rely on speech reading or interpreters. Some cochlear implantees can even converse on a voice telephone.

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[8] The term "severely" hearing impaired usually refers to an individual with a hearing loss of between 70 and 90 decibels. The term "profoundly" hearing-impaired usually refers to an individual with a hearing loss of greater than 90 decibels. Generally, hearing losses are said to range from mild to moderate to severe to profound.

[9] Hearing aids have become smaller in size, from body-worn instruments to behind the ear, in the ear, and ear canal instruments. Some other notable advances are as follows: (1) Modern hearing aids are able to amplify over a wider band, therefore assisting with speech processing; (2) compression has been introduced so that aids can amplify without distortion; (3) directional microphones assist in reducing the effects of background noise; (4) greater flexibility and adjustability make it possible to modify the frequency responses of aids; (5) prescriptive selection procedures allow more precise fitting to individual needs; (6) research in earmold acoustics has improved the coupling of hearing aids to individual wearers. *See* ROBERT E. SANDLIN, HANDBOOK OF HEARING AID AMPLIFICATION, VOL. 1: THEORETICAL AND TECHNICAL CONSIDERATIONS (1988).

[10] An FM system is a frequency modulation system that transmits sound over radio frequencies. When using an FM system, the speaker wears a transmitter and the listener wears a receiver; the sound goes directly from speaker to receiver to assist in overcoming the effects of distance and background noise. *See generally* Gwenyth R. Vaughn & Robert K. Lightfoot, *Assistive Listening Devices and Systems for Adults with Hearing Impairment*, *in* AURAL REHABILITATION (Raymond H. Hull ed., 2d ed. 1992).

Twenty years ago, most people did not foresee these seemingly Orwellian transformations. Today, however, the future seems limitless. Given the rapidly advancing state of technology, it is not unrealistic to predict that, in the foreseeable future, the technological advances of the past two decades will seem outdated. For example, it is foreseeable that cochlear implantation will enable profoundly deaf people to understand speech in most circumstances. In the past two years alone, great strides have been made in the cochlear implant field. Vastly improved hardware and software have made it possible for some implantees to discriminate speech where a year ago — even months ago — speech discrimination for those implantees was not possible.[11] We are on train number one, heading full speed ahead to *technological progress*. We are not there yet, but we are well on our way.

II. THE TRAIN TO SOCIETAL PROGRESS

Following close behind train number one is train number two: the train to societal progress. During the past twenty years, disability advocates have made great progress on the legislative front. Deaf and hearing-impaired people have joined the disability movement in lobbying for laws to protect people with disabilities from discrimination and help them become fully participating members of society. These efforts helped effect passage of the Rehabilitation Act of 1973,[12] the Individu-

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[11] For example, the cochlear implant processor produced by Cochlear Pty. Limited, was upgraded from a wearable speech processor (WSP) to a mini-speech processor (MSP). The MSP is smaller than the WSP and contains an improved speech processing strategy. *See* Colette M. McKay et al., *Speech Processing for Multichannel Cochlear Implants: Variation of the Spectral Maxima Sound Processor Strategy*, 114 ACTA OTOLARYNGOL 52 (1994); Hugh J. McDermott et al., *A New Portable Sound Processor for the University of Melbourne/Nucleus Limited Multielectoode Cochlear Implant*, 91 J. ACOUSTIC SOC'Y OF AM. 3367 (1992). Cochlear Pty. is about to place a SPEAK processor on the market, which purportedly further improves speech discrimination. M.W. Skinner et al., *Evaluation of a New Spectral Peak Coding Strategy (SPEAK) for the Nucleus 22 Channel Cochlear Implant System* (work in progress to be published in the *American Journal of Otology*). The cochlear implant equipment more recently produced by Clarion, Inc. utilizes newer and different speech processing strategies than those utilized in the Cochlear company equipment, and some experts opine that the Clarion implant will result in greater speech comprehension than the Cochlear company implant.

[12] 29 U.S.C. §§ 791-794 (Supp. IV 1992).

als with Disabilities Education Act,[13] the Americans with Disabilities Act,[14] the Fair Housing Act Amendments of 1988,[15] the Air Carriers Access Act,[16] the Television Decoder Circuitry Act,[17] and numerous other state and federal laws between 1972 and 1992.[18]

Advocates have consistently argued that because deafness is a disability, deaf people should be protected by such laws. The premise is that both the public and private sectors of society should have some responsibility for bearing the costs of deafness. Employers should be required to provide, at their expense, interpreters and other reasonable accommodations. Owners and operators of places of public accommodation should be required to do the same. Advocates demanded and received the right to interpreters,[19] TDDs,[20] relay services,[21] de-

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[13] 20 U.S.C. §§ 1400-1485 (Supp. IV 1992).

[14] 42 U.S.C. §§ 12101-12213 (Supp. III 1991).

[15] 42 U.S.C. §§ 3601-3631 (1988).

[16] 49 U.S.C. § 1374(c) (1988).

[17] S. Res. 1974, 101st Cong., 2d Sess., 136 CONG. REC. H8544 (1990) (enacted).

[18] *See, e.g.*, Architectural Barriers Act, 42 U.S.C. §§ 4151-4157 (1988); Urban Mass Transportation Act, 49 U.S.C. § 1612(a) (1988); Handicapped Children's Protection Act, 20 U.S.C. § 1415(e)(4)(B)-(F) (1988); Civil Rights Restoration Act of 1987, Pub. L. No. 100-259, 102 Stat. 28 (1988) (codified as amended in scattered sections of 20 U.S.C., 29 U.S.C. and 42 U.S.C.); Vietnam Era Veteran's Readjustment Assistance Act, 38 U.S.C. §§ 4211-4214 (Supp. IV 1992); Child Abuse Amendments of 1984, 42 U.S.C. §§ 5101-5106, 5111-5113, 5115 (1988). This list is illustrative rather than exhaustive. In addition, numerous states have enacted laws prohibiting discrimination on the basis of disability by employers and/or other entities.

[19] *See, e.g.*, 42 U.S.C. § 12102(1)(A) (Supp. 1991).

[20] *See, e.g.*, 28 C.F.R. §§ 35.161, 35.162 (1992). A TDD is a telecommunications device for the deaf. When using a TDD, the telephone receiver is placed into two headset cups (similar to a modem) on a machine that resembles a small typewriter with a video screen and/or paper printout. The TDD user types a message on a keyboard, which is relayed to a party on the other end of the line with a similar device. The receiver returns his or her message by typing it to the sender and the conversation proceeds via typewriter and video screen or printout. *See* BONNIE P. TUCKER & BRUCE A. GOLDSTEIN, LEGAL RIGHTS OF PERSONS WITH DISABILITIES: AN ANALYSIS OF FEDERAL LAW 23:2 (1990); 42 U.S.C. § 12102(1)(A) (Supp. III 1992).

[21] Because most hearing people do not have TDDs, a relay service is required to allow TDD users to communicate with non-TDD users. Thus, the TDD user calls a relay service, and a relay operator answers via TDD and

coders,[22] and other necessary and appropriate accommodations[23] at no cost to individual deaf persons. As a result, life has become less difficult for deaf people. As existing laws are enforced and new laws enacted, life should become even easier.[24] We are on train number two, headed on a fast track to *societal progress*.

III. THE DILEMMA

If care is not taken, these two fast trains are going to collide. Many members of the Deaf community, including the leaders of the National Association of the Deaf (NAD), want to get off train number one. They are not interested in pursuing technological progress, at least insofar as it involves a cure for deafness. They argue that deafness is not a disability, because nothing is "broken" that needs to be fixed. Deaf people, they claim, comprise a cultural minority of "visually oriented" individuals who should not be remade into hearing people, and their right to be Deaf should be respected.

Supporters of this view do not *want* researchers to find a cure for deafness. They do not *want* to have cochlear implants. They do not *want* to hear. They want their children to be deaf

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places the call to the non-TDD user (or vice versa). The operator then relays messages back and forth between the TDD and non-TDD users, typing messages for the TDD user and speaking messages for the non-TDD user. The ADA requires all telephone companies to provide 24 hour, seven day a week relay service for hearing and speech-impaired individuals. TUCKER & GOLDSTEIN, *supra* note 20, at 23:2.

[22] Decoders enable viewing closed-captioned television shows on "line 21" of the television screen, which is reserved expressly for that purpose. In this manner, hearing-impaired television viewers may read what is said on the screen. However, there is no legal requirement that television stations close-caption their programs. The Television Decoder Circuitry Act of 1990, however, requires all television sets manufactured in — or for use in — the United States, having picture screens at least thirteen inches in size, to be equipped "with built-in decoder circuitry designed to display closed-captioned television transmissions" at the option of the viewer. 47 U.S.C. §§ 303(u), 330 (Supp. III 1991).

[23] *See, e.g.*, 42 U.S.C. §§ 12102, 12112(b)(5)(A), 12132, 12182(b)(2)(A) (Supp. III 1992).

[24] For example, currently no law requires that federal courts be accessible to deaf and hearing-impaired plaintiffs, defendants, witnesses, jurors, and observers. *See* Bonnie P. Tucker, *The Federal Courts: Exempt from Legislation*, NAT'L DISABILITY L. REP., Sept. 18, 1991.

and to be part of the Deaf world. "We like being Deaf," they state. "We are proud of our Deafness." "Deaf is Dandy," they exclaim. They claim the *right* to their own "ethnicity, with [their] own language and culture, the same way that Native Americans or Italians bond together." They claim the right to "personal diversity," which is "something to be cherished rather than fixed and erased."[25]

They also *strongly* protest the practice of placing cochlear implants in children.[26] "[D]eaf people do not view themselves as problems in search of cures . . . [nor do they] bemoan the absence of sound but instead celebrate the prisms of vision . . . ."[27] Since "[h]earing is not a life or death matter . . . [it is] consequently not worth the medical, moral and ethical risk of altering a child."[28] The former Executive Director of the NAD, Charles Estes, claims that cochlear implants are a form of "assault . . . by zapping the auditory nerve tissue electrically," and asserts that this practice is analogous to the Iraqi invasion of Kuwait or the beating of a blind man in order to induce him to see stars.[29]

Many of these same members of the Deaf community, however, are among the strongest advocates for laws and special programs to protect and assist people with hearing-impairments. Many of them work at federally funded institutions serving deaf persons, such as Gallaudet University and the National Technical Institute for the Deaf at Rochester Institute of Technology. Others work at state vocational rehabilitation agencies or other state or federally funded entities or organizations.[30] A few work in the private sector and demand neces-

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[25] Roz Rosen, *President Rosen on Cochlear Implants*, NAD BROADCASTER, Dec. 1992, at 6 [hereinafter *Rosen on Cochlear Implants*]; *see also* Roslyn Rosen, *The President Signs On*, NAD BROADCASTER, Jan. 1991, at 3.

[26] *See, e.g.*, *Cochlear Implants in Children: A Position Paper of the National Association of the Deaf*, NAD BROADCASTER, Mar. 1991, at 1; *President Rosen on Cochlear Implants*, *supra* note 25.

[27] *Rosen on Cochlear Implants*, *supra* note 25, at 6.

[28] *Id.*

[29] Charles C. Estes, *Bestest From Estes*, NAD BROADCASTER, Jan. 1991, at 3.

[30] *See, e.g.*, ALAN B. CRAMMATTEE, MEETING THE CHALLENGE: HEARING-IMPAIRED PROFESSIONALS IN THE WORKPLACE 66-72 (1987); *Americans with Disabilities Act: Hearing Before the Subcomm. on Labor of the Senate Comm. on Human Resources*, 101st Cong., 1st Sess. 60 (1990) (testimony from the National Technical Institute for the Deaf).

sary accommodations. Still others demand the right to receive social security disability benefits, claiming that their deafness makes them unemployable. All argue strongly for the need for interpreters, TDDs, telephone relay services, specially funded educational programs, and close-captioned television shows, movies, and videos — all at no cost to deaf and hearing impaired individuals.[31] Many of these members of the Deaf community want more than merely the provision of reasonable accommodations; they argue for affirmative action in the employment arena.[32]

While fighting to get *off* the train to technological progress, these members of the Deaf community want to stay *on* the train to societal progress and would like it to go even faster — hence the dilemma. They contend that deafness *is not* a disability, but a state of being, a "right" that *should not* be altered; they also claim, however, that deafness *is* a disability for which society should compensate by providing and paying for devices, services, and interpreters to allow deaf people to function fully in society.

The dilemma is obvious. If, through technology, deaf people can improve their ability to hear to the extent that they do not require interpreters in some, many, or all situations, society will not have to pay for interpreters in those situations. If, through technology, deaf people can improve their ability to hear to the extent that they can communicate on the telephone, society will not be obliged to pay for TDDs and relay services. If, through technology, deaf people can improve their ability to hear to the extent that they can understand the teacher in a regular classroom, society will not be obliged to pay for special schools for deaf people. And so forth. And so on.

Do deaf people have the right to refuse to accept new technology, to refuse to "fix" their deafness if such repair becomes possible? Yes, absolutely. They have the right to cherish their Deaf culture, their Deaf ethnicity, and their "visually oriented" diversity. They have every right to choose *not* to fix

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[31] Deaf people, for example, were among the most prominent advocates for the American with Disabilities Act. With respect to captioned television shows, movies, and videos, the National Captioning Institute in Falls Church, Virginia, is a major national organization. It is headed by Philip Bravin, a deaf man and former chairperson of the Gallaudet University Board of Trustees. The primary purpose of the Captioning Institute is to promote captioning of television shows, videos, and movies.

[32] *See, e.g.*, DEAF STUDENTS IN POST SECONDARY EDUCATION 17-18 (Susan B. Foster & Gerard G. Walters eds., 1992).

their deafness and to believe that nothing is broken. Do deaf people have the right to demand society pay for the costs of that choice, however? No, I do not believe they do.

While reasonable adjustments should always be made to accommodate people with disabilities, unreasonable accommodations need not, and should not, be made. The premise behind the reasonable accommodation doctrine is to remove barriers blocking the full integration into society of those persons who have disabilities beyond their control. Society provides accommodations that attempt to place disabled people on equal footing with non-disabled people to the maximum extent practicable. If the disability can be otherwise alleviated, however, the reasonable accommodation doctrine becomes irrelevant. Accommodation is not required to provide equal opportunities where the condition that renders opportunity unequal may itself be eliminated.[33]

Do deaf people have the right to demand the stoppage of research aimed at finding a cure for deafness, thereby leaving other deaf people with no choice but to be deaf? Again, I do not believe they do. No individual has the right to dictate the confines of others' lives, even if motivated by an understandable desire to maintain a purported culture. Contrary to the sentiments expressed by numerous Deaf people,[34] deaf people do not comprise a cultural race in the same manner as Native Americans, Blacks, Haitians, or Hispanics. Members of these cultural races, unlike deaf people, do not lack one of the five critical senses necessary to function in society without special assistance.

Suppose that blindness and quadriplegia were "curable" due to advanced technology. Blind people could be made to "see" via artificial means such as surgical implantation or three dimensional eyeglasses and quadriplegic individuals could be made to "walk" and use their arms via artificial means such as surgical nerve implantation or specially built devices. The blind people

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[33] It is interesting to note that generally a plaintiff cannot recover damages against a tortfeasor for permanent injury if the injury could be alleviated by reasonable surgical procedures that involve minimal risk. "[It is] well established that the plaintiff in a personal injury case cannot claim damages for what would otherwise be a permanent injury if the permanency of the injury could have been avoided by submitting to treatment by a physician, including possible surgery, when a reasonable person would do so under the same circumstances." Zimmerman v. Ausland, 513 P.2d 1167, 1169 (Or. 1973).

[34] *See, e.g.*, Dolnick, *supra* note 4, at 37.

might not see as perfectly as sighted people, they might still miss some of the fine print, and the quadriplegic individuals might walk with limps or move their arms in a jerky fashion. They would, however, require little special assistance. Blind people could choose not to use available technology because they are not "disabled," but rather "auditorially oriented." Similarly, quadriplegic people could choose not to use available technology because they are not "disabled," but are simply "out-of-body oriented."

How long would society agree to pay for readers, attendants, and other services and devices to assist those blind and quadriplegic individuals who have exercised their right to be diverse? More importantly, how long should society be asked to pay for such services and devices? Do not those blind and quadriplegic individuals have the moral obligation to pay the costs resulting from the exercise of choice? Similarly, would some blind or quadriplegic individuals have the right to demand that research to cure blindness and paralysis cease, thereby denying other blind and quadriplegic individuals the right to choose for themselves whether they wish to remain blind or paralyzed? The answers to these questions are self-evident.

CONCLUSION

If deaf people bring the train to technological progress to a screeching halt, they unwittingly will block the progress of the train to societal progress. The trains will either derail or collide.

When technology advances to the extent that the choice to hear becomes a viable option for profoundly deaf people, they will have to decide whether to accept it. They have the right to remain deaf. If they do so, however, they should assume responsibility for that choice by bearing the resultant costs, rather than thrusting the responsibility upon society.

The dilemma has already begun. Is it legally and morally ethical for deaf people to claim that deafness *is not* a disability, and that research to cure deafness should therefore cease, while claiming that deafness *is* a disability for which society should compensate? I suggest that it is not. As the proverb says, "you can't have your cake and eat it too."[35]

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[35] Another aspect of this dilemma lies in the way the social security disability program is administered. Many disabled people, including deaf

The first wave message with respect to deafness focused on the "tragic" handicapping aspects of deafness. To combat this characterization, the second wave message disclaims deafness as a disability. The third wave message must recognize the valid aspects of both messages.

The first wave message properly recognized that deafness does have handicapping aspects. Deaf people cannot hear. Thus, most deaf people cannot use the telephone, hear a movie, television, radio show, or theater production, listen to a lecture or sermon, converse with people in many — if not most — everyday settings, or do thousands of things that hearing people take for granted as they go about their daily lives. To enable deaf people to do some of these things and to assist their full integration into society, deaf people require assistance in the form of accommodations.

The second wave message correctly recognizes that deafness is not necessarily tragic and deaf people are fully capable of standing on equal footing with hearing people. Deaf people are not "poor disabled people" to be pitied, patronized, and looked down upon.

The third wave movement must recognize the valid aspects of both messages and balance their competing themes.

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people, receive social security disability benefits because they are allegedly unemployable due to their disabilities. Some severely disabled people clearly are unemployable. Few deaf people, however, should fall in that category. Now that Title I of the ADA requires private employers to refrain from discriminating against persons with disabilities and requires private employers to provide reasonable accommodations for disabled employees, the employment arena is becoming vastly more accessible to all people with disabilities. *Cf.* 42 U.S.C. §§ 12111-12117 (Supp. III 1992). The current scope and application of our social security disability system seems to conflict with the premise of laws such as the ADA.